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## CLINICAL PSYCHOLOGY & NEUROPSYCHOLOGY | RESEARCH ARTICLE

# Partners' experiences of relationship continuity in acquired brain injury

Darrelle Villa<sup>1</sup> and Gerard A. Riley<sup>1\*</sup>

**Abstract:** *Background:* Research in dementia suggests that spousal carers differ in terms of whether they perceive their relationship with the person with dementia as continuous with the pre-morbid relationship or as radically changed, and that these differences may be associated with how spouses respond to the challenges of care-giving. The aim of this study was to explore whether the conceptual framework of relationship continuity (which comprises five dimensions) may also be applicable to understanding the experience of spousal carers in acquired brain injury. *Method:* Five spouses were interviewed about their relationship, and the data were analysed using Template Analysis. The applicability of the framework was evaluated by assessing (1) whether the accounts of each participant provided material relevant to each of the five dimensions of relationship continuity, and (2) whether the accounts suggested a close link between the dimensions (i.e. whether participants who showed continuity on one dimension tended to show continuity on the other dimensions). The association between continuity/discontinuity and responses to the challenges of care-giving was also explored. *Findings:* Findings suggested that the two criteria were met and that the framework may be useful in understanding the experience of spousal carers in brain injury. Furthermore, those who perceived discontinuity drew on medical models for making sense of changes in their partner, experienced

### ABOUT THE AUTHORS

The authors have an interest in the impact that acquired brain injury has on family relationships. A major theme in their research is how some partners perceive that the brain injury has radically changed the person with the injury, and their relationship with that person, whereas others perceive continuity in the person and relationship. Their research has focused on exploring the impact of this difference on how partners cope emotionally and on the nature of the care and support that they provide.

### PUBLIC INTEREST STATEMENT

In this study, five partners of people with a brain injury were asked to describe the person with the injury before and after the injury, and their relationship before and after the injury. For some participants, the person with the injury felt like a stranger, and their relationship no longer felt like a marriage; but others experienced the other person and their relationship as being essentially the same as before the injury, despite changes brought about by the injury. Those who experienced the person and the relationship as radically different felt grief for the pre-injury person they had lost, and felt less love and affection towards the post-injury person. They tended to make sense of changes in their partner solely in terms of the injury itself (rather than using their knowledge of the person as an individual), to report more reliance on external help for managing those changes, to find the care-giving role more burdensome, and to express more doubts about remaining within the relationship.

greater subjective burden, and expressed doubts about remaining within the relationship. Those who perceived discontinuity also reported experiencing less warmth and affection from their partner.

**Subjects:** Clinical Neuropsychology; Neuropsychological Rehabilitation; Intimate Relations

**Keywords:** brain injury; care-giving; burden; family relationships; marriage; marital satisfaction; template analysis

## 1. Introduction

It is important to understand the impact that acquired brain injuries (ABI) (such as traumatic brain injury, stroke and tumours) can have upon on spousal relationships (“spousal relationships” is used loosely here to refer to both marriages and partnerships). Low levels of relationship satisfaction, and high rates of separation and divorce, have frequently been reported after ABI (Blais & Boisvert, 2005; BurrIDGE, Williams, Yates, Harris, & Ward, 2007; Godwin, Kreutzer, Arango-Lasprilla, & Lehan, 2011; Gosling & Oddy, 1999; Wood & Yurdakul, 1997). Poor quality relationships may, in turn, have a negative impact on the general psychological well-being of both parties (Anderson, Parmenter, & Mok, 2002; Epstein-Lubow, Beevers, Bishop, & Miller, 2009; Kendall & Terry, 2009), and on the rehabilitation outcomes for the person with the ABI because of the important role the spouse plays in helping the person achieve those outcomes (Clark & Smith, 1999; Palmer & Glass, 2003; Sander et al., 2002). A better understanding of how ABI affects spousal relationships may facilitate the development of more effective methods of supporting couples to maintain an enduring and satisfying relationship that promotes their psychological well-being and the rehabilitation outcomes of the person with the ABI.

In the context of dementia, “relationship continuity” is a conceptual framework that has been used to understand the impact of dementia on the spousal relationship from the perspective of the spouse (Chesla, Martinson, & Muwaswes, 1994; Gladstone, 1995; Kaplan, 2001; Riley et al., 2013; Walters, Oyebode, & Riley, 2010). Riley et al. (2013) defined the concept of relationship continuity in terms of whether the spouse of the person with dementia experiences the relationship as a continuation of the pre-morbid relationship (continuity), or as essentially changed and radically different (discontinuity). Whilst all relationships inevitably undergo change following significant brain dysfunction, it is whether the essence of the relationship survives the change that distinguishes experiences of continuity from discontinuity. Based on a synthesis of qualitative research on this topic, Riley et al. proposed five dimensions of relationship continuity, each dimension providing a contrast between continuity and discontinuity: *Relationship redefined* (continuity—the relationship is viewed as a continuation of the pre-morbid relationship; discontinuity—the spousal relationship is viewed as finished and replaced with a new type of relationship); *same/different person* (continuity—the person with dementia is seen as essentially the same despite dementia-related changes; discontinuity—the person is perceived to have changed in a fundamental way); *same/different feelings* (continuity—the spouse continues to feel the same love and affection for their partner; discontinuity—these feelings have been replaced with others, such as feelings of protectiveness or emotional detachment); *couplehood* (continuity—the sense of being one member of a couple is retained; discontinuity—the spouses view themselves in an individualistic way); and *loss* (a sense of loss for the pre-morbid person and relationship may be felt by those spouses experiencing discontinuity, but not by those experiencing continuity). These five dimensions are viewed as being intimately connected (Riley et al., 2013). For example, a perception of the other person as a stranger is considered highly likely to result in a perception that the relationship is also very different; and a sense of loss for the pre-morbid person and relationship presupposes fundamental changes in the perceptions of how that person and relationship are viewed. Evidence for these close connections was provided by the high correlations between subscale scores of a questionnaire measuring the different dimensions (Riley et al., 2013).

The value of this conceptual framework in dementia rests partly on this ability to connect different aspects of the spouse's experience, thereby providing a richer understanding of that experience. Of particular relevance in the present context, its value also derives from the links that have been made in the qualitative research between, on the one hand, relationship continuity and, on the other, satisfaction with the relationship and the nature of the care and support provided by the spouse. For example, relationship continuity has been associated with deriving more positive meaning and gratification from the caring role (Chesla et al., 1994), whereas discontinuity has been associated with feelings of entrapment and resentment towards the other person (Walters et al., 2010). A recent study has provided quantitative support for this association (Riley, Evans, & Oyeboode, *in press*). Continuity has also been linked with a more empathic and person-centred approach to providing care and support that is tailored to the needs of the individual (Chesla et al., 1994; Walters et al., 2010); whereas discontinuity has been linked with a depersonalised perception of the person with dementia, and a more restrictive approach to the provision of care (Lewis, 1998; Walters et al., 2010).

The concept of relationship continuity resonates with some findings in existing ABI research. Echoing the *same/different person* dimension, Gosling and Oddy (1999) reported that over half of the spouses in their study endorsed the questionnaire item, "My partner has felt like a stranger to me since the injury". The experience of the injured spouse as a "stranger" has also been reported by others (Bodley-Scott & Riley, 2015; Gill, Sander, Robins, Mazzei, & Struchen, 2011; Kratz, Sander, Brickell, Lange, & Carlozzi, 2017; Mauss-Clum & Ryan, 1981; Oddy, 1995; Wood, 2005). For example, in a qualitative study of spousal relationships after traumatic brain injury, Gill et al. (2011) reported a list of factors that were perceived by uninjured spouses to act as barriers to intimacy in the relationship and this list included the perception of the injured partner as a different person. Echoing *relationship redefined*, participants also discussed how they felt more like a parent than a spouse and that this was inconsistent with intimacy. Similarly, Gosling and Oddy (1999) reported that over half of their participants experienced the relationship to be more like a parental than a spousal role. Relevant to the *couplehood* dimension, some participants in this study by Gosling and Oddy also described the loss of a sense of an equal and sharing relationship; whilst Anderson-Parenté, DeCesare, and Parenté (1990) reported that spouses who had remained in a relationship with their partner with a brain injury highlighted their alliance with their partner against the shared problems posed by the brain injury as one of the reasons why they had stayed. With respect to *same/different feelings*, some of the participants in the study by Gill et al. reported finding it difficult to feel close to their partner and expressed some negative feelings towards them such as anger and resentment; whereas others expressed their continuing love and affection. Similar findings were reported by Bodley-Scott and Riley (2015), Gosling and Oddy (1999), Godwin, Chappell, and Kreutzer (2014) and Hammond, Davis, Whiteside, Philbrick, and Hirsch (2011). With respect to *loss*, a period of grief for the person that has been lost was a feature of the stage models of family adaptation to traumatic brain injury that were developed in the 1980s (e.g. Groveman & Brown, 1985; Lezak, 1986). Feelings of loss and grief have also been reported by some spousal carers in more recent qualitative studies (e.g. Bodley-Scott & Riley, 2015; Godwin et al., 2014; Hammond et al., 2011; Kratz et al., 2017; Ruston, 2007).

Although there is evidence in the ABI literature that suggests the applicability of relationship continuity as a framework for understanding some changes in the relationship, this evidence was not explicitly related to relationship continuity by most of the original researchers. It was also not gathered in a systematic way: findings relevant to relationship continuity have often been peripheral to the main objectives of the study and listed amongst a range of other findings. Furthermore, it cannot be assumed that the experiences of spouses of people with ABI will necessarily show similarities to those of people with dementia: Dementia follows a course of progressive deterioration over time, but, after a severe ABI, there is typically an improvement that is rapid in the early months, but that gradually slows and plateaus. Thus, in the context of ABI, the concept of relationship continuity has not been investigated in any depth and its usefulness cannot be assumed.

The primary aim of the present study, therefore, was to explore whether the framework of relationship continuity may be useful in describing and understanding the experiences of spouses following

ABI. In a qualitative study using Template Analysis, five participants whose partners had an ABI were asked to give an account of their past and current relationship with their spouse. The five dimensions of relationship continuity, described earlier, formed the template for the analysis of the data; that is, the dimensions were used as predetermined themes, and data that corresponded to each dimension/theme were grouped together. Two criteria were used in judging the usefulness of the framework in describing and understanding their experience. The first criterion was whether the account of each participant provided material relevant to each of the five dimensions. Given that participants were providing their own narrative about the relationship, the collection of data relevant to each dimension from each participant would be an indication of the usefulness of the framework insofar as it would provide evidence that the dimensions map onto the participants' own ways of making sense of their experiences of the relationship. The second criterion was whether the narratives of the participants suggested a close linkage across the five dimensions; in other words, whether participants who showed continuity (or discontinuity) on one dimension tended to show continuity (or discontinuity) on the other dimensions. Findings in dementia research suggest that the five dimensions are closely connected in this way. The applicability of relationship continuity as a framework in the context of ABI would be called into question if these connections were not apparent. A secondary aim of the study was to explore potential connections between relationship continuity and how the participants responded to the demands of care-giving. Such connections have been proposed in the dementia literature (e.g. Chesla et al., 1994; Walters et al., 2010). The value of the relationship continuity framework in an ABI context would be further enhanced if similar connections were evident in the present study.

## 2. Method

### 2.1. Ethics

Ethical approval was obtained from the UK's National Research Ethics Service.

### 2.2. Participants and recruitment

Participants were required to be marital or long-term partners of working age adults who had suffered a moderate or severe ABI at least 1 year but no more than 10 years previously. They were required to be cohabiting at the time of the injury and at the time of the interviews; and the length of the pre-injury relationship was required to be a minimum of 10 years. These time-related criteria were set to ensure that the participant's experience of the ABI occurred in the context of a relatively well-established relationship (at least 10 years) with which the current relationship could be compared; that the participant's recollection of the pre-morbid relationship was relatively detailed (ABI occurred no more than 10 years previously); and that the participant had adequate time to reflect on their experience of the current relationship (ABI occurred at least one year previously). Exclusion criteria included a current diagnosis of a severe mental health disorder or a pre-existing significant disability in the care-giving spouse or individual with ABI, and lack of fluency in spoken English in the care-giving spouse.

Potential participants were identified through an out-patient brain injury service of the UK's National Health Service and through branches of Headway, a UK brain injury charity. It was intended to recruit a sample of between 5 and 10 participants. "Data saturation" (i.e. continuing to interview more participants until no new themes emerge) is sometimes proposed as the basis for determining sample size in qualitative research (Francis et al., 2010). However, this was not appropriate in the current study because the themes were pre-determined. Moreover, when there is a focus, as in the present study, on a detailed understanding of the experience of the participants and on exploring individual differences between participants, large samples are impractical in terms of analysis and reporting, and smaller samples are recommended (Morse, 2000; Smith, Flowers, & Larkin, 2009).

Six people were interviewed. Data from one participant were not included in the analysis because she became emotionally distressed and requested that her interview was terminated. Table 1 provides some demographic and injury-related information about the remaining five participants and their partners.

**Table 1. Participant characteristics**

Participants		Spouses with ABI				
Pseudonym	Age	Pseudonym	Age	Cause of brain injury	Length of pre-injury relationship (years)	Time post-injury (years)
Frank	66	Wilma	52	TBI—fall	25	1
Janet	52	Jeff	52	TBI—road accident	34	1
Joan	55	Matthew	62	Stroke	20	10
Maureen	51	David	50	TBI—road accident	28	3
Claire	54	Nick	57	TBI—road accident	25	2

### 2.3. Interviews

Each participant was interviewed on two separate occasions approximately a week apart. The first interview explored aspects of the pre-injury relationship, while the second interview focused on the post-injury relationship. One aim of the study was to determine whether the self-generated narratives of the participants about their relationship contained material that mapped onto the pre-determined conceptual framework of relationship continuity. It was important, therefore, that no questions were asked that used terminology or concepts associated with relationship continuity. Rather, the interview schedule asked, in relation to both time before and after the injury, about enjoyable times and memories; the strengths of the relationship; how they spent time together; how they dealt with difficult situations as a couple; and difficulties and challenges within the relationship. Participants were also asked to provide five words to describe their partner and the relationship, both before and after the injury. To access aspects of the narrative that may relate to loss and grief, participants were asked whether they thought much about their life before the injury.

### 2.4. Qualitative analysis

Given the primary aim of the research (to determine whether a pre-existing conceptual framework was supported by sufficient data from the narratives of participants, and whether these narratives suggested close associations across the various dimensions of the framework), a theory-led analysis was required in which the five dimensions of the relationship continuity framework could be used as predetermined themes. One qualitative approach that promotes the use of predetermined themes is Template Analysis (King, 2012). Predetermined themes are seen as a useful way of focusing the analysis on the research questions and on issues expected to be relevant on the basis of previous research. However, the approach also encourages the development or rejection of these themes, and the development of new themes, according to what is suggested by the data. Early transcripts are coded using the predetermined themes and any other themes considered relevant to the research questions. An initial template is then produced in which definitions are provided for any new themes and any modified predetermined themes, and themes are grouped into broader categories where possible. This initial template is then used to code subsequent transcripts, and is modified as necessary to provide a satisfactory representation of the data.

Template analysis was accordingly used in the present study. The five dimensions of the relationship continuity framework were used as predetermined themes (i.e. *relationship redefined*, *same/different person*, *same/different feelings*, *couplehood* and *loss*). The interviews also generated a wide range of material on other issues. Some of this material was relevant to the secondary aim of the study (i.e. to explore potential associations between relationship continuity and dealing with the challenges of care-giving) and therefore new themes were also established to capture this material.

In terms of epistemology, a phenomenological focus was adopted: the interest was in how the participants experienced and made sense of their relationship, rather than on some objective reality or



social construction separate from their experience. Consistent with this, there was no attempt to uncover any latent meaning that the statements of the participants might have, either during the interviews or within the data analysis. This is a particularly important consideration, given the aims of the study. One of the criteria for judging the usefulness of the framework was whether the dimensions of relationship continuity map onto the participants' own self-generated narratives about the relationship. It was therefore important that additional interpretations and meanings were not imputed to those narratives. This is not to say that the researchers have not brought their own idiosyncratic influence to bear on the research. It is acknowledged that the researchers have influenced the outcome of the research in terms of how the interviews were conducted and how the data were analysed.

### 2.5. Credibility

Using interview transcripts, the two authors reflected together on how the interviews were being conducted, to ensure that the participants were not being asked leading questions that might bias them towards a narrative that incorporated relationship continuity. Subsequently, they reflected on the analysis, in order to ensure that the themes and the template were adequately grounded in the data. In this report, excerpts from the interviews have been frequently used so that this grounding is transparent to the reader. A person unconnected with the research coded one of the transcripts using the final template. Apart from some minor omissions, this coding corresponded closely to that produced by the authors. A brief summary of the findings of the study was sent to the participants and they were invited to comment, but none replied. An account of the findings was also presented to a group of clinicians specialising in acquired brain injury. None questioned the credibility of the findings and there was consensus that the themes resonated with their own experience of accounts provided by spousal carers. The fact that the findings echoed reports from previous research (see the Discussion) also lends credibility to the conduct of the interviews and the analysis of the data.

### 3. Findings

The first part of this section addresses the primary aim of the research, i.e. whether relationship continuity provides a satisfactory framework for understanding the experience of the participants. Material relevant to each of the five dimensions of relationship continuity is presented. On the basis of this material, it is then considered whether the two criteria for establishing the applicability of the concept of relationship continuity were met. The subsequent part of the Findings section addresses the secondary aim of the research, i.e. to explore potential connections between continuity and how the participants responded to the challenges of care-giving. Themes are presented that address the potential implications of continuity/discontinuity for how the participants dealt with negative aspects of their situation (*making sense of, and managing, the changes; the burden of care-giving; and thoughts about remaining within the relationship*). An additional theme describes how *lack of emotional reciprocity* may contribute to the experience of discontinuity. All the themes are summarised in Table 2.

**Table 2. Summary of themes**

- (1) Is relationship continuity an appropriate framework for conceptualising participants' experience?
  - (a) Same/different person
  - (b) Relationship redefined
  - (c) Same/different feelings
  - (d) Couplehood
  - (e) Loss
  - (f) Were the two criteria for establishing applicability met?
- (2) Potential implications of continuity/discontinuity for the response to the care-giving role
  - (a) Making sense of and managing the changes
  - (b) The burden of care-giving
  - (c) Thoughts about remaining within the relationship
- (3) A potential precursor of discontinuity
  - (a) Lack of emotional reciprocity

### 3.1. Same/different person

All participants identified post-injury changes in their spouse. However, while Frank, Joan and Maureen experienced their spouse to be so fundamentally changed that they were considered to be a different person, Claire and Janet retained a sense of their spouse still being the same person despite the changes. Joan made frequent references to her husband not being the “Matthew as he was” and remarked, “Matthew’s gone. He’s not there. [crying] He’s not my Matthew”. Maureen referred to David as “not the man I married” and said “there’s nothing ... his character- there is no character ... empty, I suppose”. Referring to a period when he first came home from hospital, she said: “My naivety was he would still- okay, disabled- but he would still be the same person that I married—not realising that he’s not and he will never be”. Frank drew a strong contrast between his wife before and after the injury:

In the first [interview] I described Wilma as sweet, cooperative, looked after herself, cared for others, put others first. Since the accident, it’s not been like that. The only one that comes first is Wilma. Who comes second is Wilma. Who comes third is Wilma. It’s Wilma. If there’s anybody else hurt or in trouble, bad luck. (Frank)

In contrast, for Claire and Janet, there was a sense that their partner remained fundamentally the same. When asked to summarise her husband’s post-injury in five words, Claire’s description referred to similar characteristics that she had used in the previous interview to describe his pre-injury: “Well, he’s very loving ... and caring and considerate ... thoughtful ... sensitive”. For Janet, although some things had changed, the essence of her husband was the same:

Because he is different in lots of ways, but his core essence I think is still- but you see I know him extremely well—so his, yeah, I still think his essence is still the same to be quite honest. It’s just how he uses it. He’s still a very proud man. He’s still quite persistent in his views ... still loves his family. He still ... you know a lot of things haven’t changed. Um he probably, his emotions are probably more to the fore so he’s, he’s still very protective, but all these things are enhanced and heightened. (Janet)

### 3.2. Relationship redefined

Frank, Joan and Maureen appraised the relationship as being defined by the care-giving, and no longer a spousal one. Maureen stated, “To be honest, I just feel like a carer ... There’s, there’s nothing else, you know”. Frank described the change in their relationship from a marital one to a parental one that was defined by responsibility and duty:

Unfortunately you feel more like a father than you feel like husband, lover or all of that ... Somebody’s got to be here to give her her tablets. Somebody’s got to be here to make sure she doesn’t hurt herself or, if she falls, to do what you’ve got to do. Somebody has to be here and I just, I see that as, in a sense, a responsibility. (Frank)

Joan similarly defined the post-injury relationship in terms of the provision of care: “What relationship? That’s where I would start really. Because there isn’t a relationship. I look after Matthew ... Matthew’s in the house. I feed him. I water him ... That’s, that’s the ‘couple’”.

In contrast, although Janet described having to take on far greater responsibilities in the running of the household, she described the relationship as being “slightly” different, but essentially the same:

I suppose in that way [being less stormy and volatile], it [the relationship] has changed slightly. But not drastically. You know, we’re still basically the same ... perhaps the goalposts have moved or the rules are different or, you know, we’re playing with one leg, rather than two but it- it’s still- in essence it’s still the same. (Janet)



Claire acknowledged the introduction of a protective aspect to the relationship that had not been there previously, but, in contrast to Frank, Joan and Maureen, this ran alongside the spousal relationship, rather than replacing it.

Before, we were just, you know, we were a couple, a married couple, husband and wife, which we still are; but now I also feel more like a mother in a way, looking after a- not a child—but just looking out for your ... your child, you know. (Claire)

### 3.3. *Same/different feelings*

Claire was unambiguous in her expression of love and affection towards Nick, although they had been joined by feelings of protectiveness: “We get on really well ... I just love Nick so much and I feel really protective towards him”. The other participants, however, were more ambivalent about how they felt. Janet expressed her continuing love for Jeff, but she felt that this did not sit easily at times with the changing role she had within their relationship and said there were times when other more negative feelings were triggered.

This is where I get a bit confused because I still love Jeff, don’t get me wrong, but I think my feelings have changed ... and I think it’s because of the role that I play. So [sighs] I don’t know. It’s hard. It is difficult. But when Jeff, when my Jeff is there, it’s quite easy. But when, I mean sometimes he can throw a fit because he doesn’t want to do something ... I do find that is, I think your feelings change then. (Janet)

Maureen similarly described how her emotional connection and love towards David was still there, but that it was accompanied by other more negative feelings.

And I still do love him, although he’s not the man I married. It’s still there, you know, and I don’t, as I say to you, if you’ve got that chemistry, I don’t think it ever goes, does it? ... But I do feel bitter ... Don’t get me wrong, I’m very loyal to him and I love him. There’s a lot of resentment...I do feel bitter. (Maureen)

Frank thought that he must have some love for Wilma, but this was based on the fact that he was still in the relationship rather than a description of his feelings. He went on to wonder whether it was pity that kept him in the relationship, and he reflected on the difficulty of loving and pitying someone at the same time: “I think, I- well I must still love her because, if I didn’t, I wouldn’t be here. Yeah, yeah I wouldn’t be here so there’s, must be ... pity. It’s just hard feeling sorry for somebody and loving them”.

Joan more openly expressed ambiguity about whether she still loved her partner. She described a shift from the certainty of her feelings of love for Matthew throughout the tribulations of their pre-injury lives (“I never stopped loving Matthew through anything”) to present uncertainty about how she feels: “Because I do love him. I did love him. I do love him. Did love him. Don’t know where that sits at the minute”. She also described times when she wished that the stroke had killed him “because you [Matthew] are not the person you were and you never will be”.

### 3.4. *Couplehood*

All participants highlighted in their pre-morbid relationship a strong sense of togetherness in terms of shared enjoyment of one another’s company, shared interests and goals, and facing challenges together. For Joan, Maureen and Frank, this sense of togetherness had been lost to a large extent. A central theme in Joan’s narrative of her pre-injury relationship was what she described as the “magic of being together”. In contrast, the experience of separation she described post-injury was stark: “But we’re not together ... We’re not together. We might sleep in the same bed, but we’re not together”. Maureen similarly described feeling separate despite shared time and space: “We sit there in the two chairs, watching the television ... No conversation, nothing”. She also described feeling “very lonely”. Frank described a sense of togetherness pre-injury which centred not only on pleasure in shared company but facing challenges together as a couple. The disappearance of the sense of

working together to meet challenges prompted Frank to question what remained of their relationship: “And you get through all that [the challenges that they faced as a couple pre-injury], but when you haven’t got that [what have you got]?”.

In contrast, Claire and Janet described a continued sense of pleasure from spending time with their partner and a feeling of working together to meet the challenges presented by the injury.

Sometimes he, like last night, we were watching a bit of television and there was something on that was quite funny and we were both laughing at it. That, you know, those are the nice things and being together. (Claire)

We still do have a lot in common ... We had lots of interests that we both enjoyed. And we enjoy, still do, enjoy each other’s company. (Claire)

We still talk at night, you know ... we still, even if we’re together for the day, we still reflect on it. (Janet)

It [the general situation] is manageable. We’ll, you know, we’ll work it out. But I still think that is down to the fact that we are partners, you know. We’ve been together a long time and we are, you know, we are partners—so I think that’s got a lot to do with it. (Janet)

However, consideration of why she wanted to return to work prompted Janet to reflect that the partnership was not quite what it used to be:

I’d like to go back to work. I’d like to do certain things for me because that’s what I always did- no, that’s the wrong way to put it because it wasn’t really for me; things used to be for us. It seems as though that we’re not, we’re not, it’s not “me and him” but it’s not quite “us”. (Janet)

### **3.5. Loss**

Joan was the only participant explicitly to use the language of loss and grief to describe how she felt when reflecting on how things had changed: “Because it’s such a- it’s, it’s a loss, and for five years I grieved for Matthew. He was not there, he’d gone”. Of the other participants, Frank came closest to using the language of loss in describing how he felt: “This year I got a different wife and that breaks my heart”. Although Claire, Janet and Maureen were upset about some of the changes in their partner, they described their experience using words such as “upset” and “sad” rather than those referring to loss or grief. Indeed, rather than focusing on loss, Janet spoke about her relief that Jeff was still alive.

It does upset me to think, when I look at him and I think how he used to be ... and how he is now. (Claire)

It is sad, very sad that certain things, you know, as I say, are very different. (Maureen)

I mean it might be the first time you notice things and you think, “Ooh ... that’s not quite you”. But then you get over that ... because it’s, you know, it’s there and you can’t do, you know. I don’t want to change what he does because, you know, I’m just glad to have him here. (Janet)

### **3.6. Were the criteria for the applicability of the framework met?**

Two criteria were set for assessing the usefulness of relationship continuity in understanding the experience of spouses of someone with an ABI. The first was whether the participants’ self-generated narratives about their relationship mapped onto the dimensions of the framework, and, more specifically, whether the account of each participant provided material relevant to each of the five dimensions. As will be evident from the use of quotations from each participant in each of above sections relating to the dimensions, this criterion was met. The second criterion concerned whether

**Table 3. Suggested location of each participant on each dimension of relationship continuity**

Dimensions	Continuity	Unclear or showing aspects of both continuity and discontinuity	Discontinuity
Same/different person	Claire, Janet		Joan, Frank, Maureen
Relationship redefined	Claire, Janet		Joan, Frank, Maureen
Same/different feelings	Claire	Janet, Maureen, Frank	Joan
Couplehood	Claire	Janet	Joan, Frank, Maureen
Loss	Claire, Janet, Maureen	Frank	Joan

participants who showed continuity (or discontinuity) on one dimension tended to show continuity (or discontinuity) on the other dimensions. Based on the material described earlier in relation to the five dimensions, Table 3 provides a summary of where each participant fell on each dimension. This suggests that the criterion was reasonably well met. Although there was by no means a perfect correspondence across dimensions, the table indicates that Clare and Janet consistently fell towards the continuity end of each dimension, Frank and Joan consistently fell towards the discontinuity end, and Maureen showed the least consistency.

This relative consistency across dimensions suggested that it would be meaningful to explore some possible connections between relationship continuity and other aspects of the participants' experiences. Four further themes address these possible connections.

### **3.7. Making sense of, and managing, the changes**

This theme focuses on the ways participants made sense of, and responded to, challenging changes in the person with the injury. Broadly, Frank and Joan, the participants who experienced greater relationship discontinuity, tended to draw on medical models for making sense of the changes and to look for external support to assist them in managing them. In contrast, Janet and Claire, the participants who retained greater continuity, drew on their pre-injury knowledge and understanding of their spouse to understand and cope with the changes.

Thus, Frank and Joan tended to attribute change directly to the brain injury, with little reference to the pre-injury personality or current circumstances of their spouse. For example, when discussing Wilma's aggressive behaviour, Frank stated:

I think I understand why Wilma's the way she is and, why I say that is that ... comes back to what I've read and what I've been told about what happens to people that have brain damage ... back to that chart I've got. Everything comes back to that brain damage. (Frank)

Similarly, Joan's explanations of change centred on the damage to Matthew's brain. Someone had suggested to her that they should attend Relate (a non-governmental service offering support for spousal relationships in crisis). Her response was that this would be futile because the changes in his ability to relate to her were due to irreversible damage to his brain.

This isn't marriage difficulties. This is somebody whose brain has been bugged up. I think Matthew has lost, is it thirty percent of the right side of his brain? a big chunk of his brain ... or is it forty percent? I don't know. Massive bit of brain—dead. But lots of change did happen. He just didn't make those connections on caring and loving and relationships. Not at all. That's not going to happen and that won't happen now. No bloody Relate's going to switch that on because I think it's too late. (Joan)

Given this reliance on an understanding of the changes in terms of damage to the brain, both Frank and Joan understandably expressed the need for external support to manage the challenges of

brain injury. Frank described how he had tried his best to deal with Wilma's difficult behaviour, but now needed help from "experts":

I'm fairly inventive and I've tried absolutely everything whether it's being calm, trying to reason with her. But that doesn't work obviously. I've tried yelling... but now it's diff- I've got to get the care because I've done what I can do and I now need somebody or groups of somebody to say, "you might try this". (Frank)

Joan described her frustration over the fact that the rehabilitation service that Matthew had attended had helped him do practical things, but had failed to address the changes that she found most difficult:

They've been very clever. They have put on the lights for his walking, his talking. He can make cup of tea. He now can cook a dinner, sort of—he might start it way early. But they've done those skills. So where have you switched on Matthew's other part of the brain to be loving? (Joan)

In contrast, rather than relying on an explanation in terms of brain damage, Janet's narrative indicated that she drew on her understanding of Jeff's personality, combined with her knowledge of current circumstances, to make sense of and manage post-injury changes. An example of this can be seen in the way she made sense of Jeff's argumentative behaviour:

When Jeff was at home a lot, it [i.e. his argumentative behaviour] happened more ... and I think it's because of his, his nature and his intelligence. He's not used to staying with one person every day. He's just not. He's a very social person, you know. (Janet)

In trying to support and motivate Jeff, Janet used these more individualised explanations to guide her efforts. For example, she made use of his competitiveness when he was learning how to walk again by encouraging him to compete against a toddler within the family who was learning to walk: "He's very competitive... so the competition side of it was like, even though it was against a little baby, it was still there so we used that to our advantage". Rather than looking for solutions externally, Janet described finding answers by using her own knowledge and understanding of Jeff: "I don't look on the internet about this, that and the other... we take it each day as it comes and we, you know, I try to stick to a format that Jeff understands". Similarly, Claire related Nick's tendency to get upset over trivial matters to his pre-injury "sensitivity". Her method of responding to his upset (to provide him the opportunity to talk about the matter, and provide sympathy and reassurance) matched how she responded to his pre-injury sensitivity.

Maureen also made use of her understanding of David's pre-injury personality to explain some of his current difficulties. For example, describing David's refusal to attend Headway, she said:

Because David never did anything he didn't want to do. He was very strong-willed. And so people making him do these things, going there, having carers, he didn't like it, because it wasn't his say ... because decisions were taken away from him ... Although we made decisions together [pre-injury], he sort of had the last say and always had his own way. He was very spoilt as a child. (Maureen)

However, unlike Janet and Claire, Maureen provided no examples of using this knowledge of David as an individual to manage the changes.

### **3.8. The burden of care-giving**

Although all participants described the experience of caring for their partner as a significant challenge, it seemed to be particularly burdensome for those participants who more consistently expressed discontinuity (Frank and Joan) compared to those who more consistently expressed continuity (Janet and Claire).

For Frank and Joan, there was the sense that the challenge of caring for their partner was at times more than they could cope with. Asked if there was anything good about their life together at the moment, Frank replied: “No. Because, whatever, day-to-day, minute-to-minute, hour-to-hour, it’s all horrible”. Frank told a story of how he threatened to stop caring for Wilma that illustrated how desperate he felt at times:

She [mental health clinician] said, “Well ... what are you going to do now?” “Oh not much” I said “Well I tell you what. I’m leaving the door open. She knows where the tablets are. She can just walk out. Get killed, probably kill someone else and you can come to the funeral next week”. (Frank)

Joan described how she would often think to herself: “How much more of this can I cope with?”

In contrast, Claire and Janet both described themselves as coping reasonably well, despite all the difficulties. Claire said, “I feel like I am coping with it quite well”; and Janet similarly remarked, “I don’t find that things are unbearably different. Let’s put it that way. They’re not, you know, they’re quite cope, they’re manageable and I’m coping with them”. Likewise, Maureen felt that she was coping well and that the situation was not unbearable: “You know, I’m quite happy caring for Dave”. Possibly, this was because she perceived herself as being someone to whom the caring role came more naturally (“I’m a nurturer”) and because their pre-morbid relationship had been characterised, in part, by Maureen needing to “look after” Dave.

### **3.9. Thoughts about remaining within the relationship**

Joan and Frank, who showed the most discontinuity, both reported that they had thought about ending the relationship. Joan said, “I have thought about leaving him. Kicking him out. Doing all that”. She described how she had once “got really excited” about the possibility of him moving out to supported accommodation. Similarly, Frank had thought about ending the relationship:

What else is there really? For me? Sad isn’t it? If I could walk away, that would be different ... But I just have to, really have to, keep going that’s ... it’s been a couple of times when I could just walk out and but, err, no, no couldn’t do that. Well not at the moment. (Frank)

Claire and Maureen, by contrast, were clear about their ongoing commitment to the relationship, dismissing the possibility of separation. Reflecting on the suggestion that someone had made about David going into residential care, Maureen said:

But I could never do that, because I am very loyal to him and I still love him... I know I could have walked away but I would never have done that, and I think it is because—it’s my loyalty and love to David. (Maureen)

Similarly, Claire was insistent that separation was not a possibility:

I did read in that article that seventy-five percent of marriages usually end up being divorced or splitting up, for people who have had one of the partners who’s had a brain injury. And I can’t see that happening to me and Nick because, you know, I, I love him so much and, you know, he depends on me. (Claire)

### **3.10. Lack of emotional reciprocity**

Joan, Frank and Maureen highlighted the lack of warmth, affection and empathy from their partner as being something that they found particularly difficult. For Joan, intimacy, affection, passion and excitement were central to her pre-injury relationship: “It was magical...and good times like that that were exciting and, and loving times, you know”. The contrast in his lack of post-injury warmth was something she found particularly difficult: “Can’t even throw an arm across you. Nothing. Nothing....Matthew’s in the house. I feed him. I water him ... There is no loving, holding. There is no

loving, holding, sexual, in any shape or form. That's all gone". Frank described how Wilma had been "lovey dovey" prior to the injury but that this had gone, and he missed it:

You wake up in the morning; "How are you?"; "Got a headache. Feel bad". Absolutely nothing, nothing positive, nothing pleasurable. Going to give, put my arm around her or something, "What do you want to do that for?" ...It's all negative, negative, negative. (Frank)

Maureen reflected on David's lack of consideration and thoughtfulness towards her. Prior to the injury he used to buy her gifts, but this had stopped:

Although, you know, it's not the material things that should matter, they still keep a little bit of a spark, you know, to say, "Oh, you know, he did think". And now he doesn't think about me or anything else at all.

In contrast, Claire and Janet (who perceived greater continuity in their relationships) reported examples of the affection and consideration that they continued to receive from their partner. Janet described how they were both "still caring towards each other"; and Claire described how loving and considerate her partner is:

I feel like we're always hugging each other now, and he calls me "my love" and I call him "my love" ...I just think he's very thoughtful and considerate. It was our wedding anniversary last week and he bought me a lovely card and he also made me a pottery thing ... And he, he did, he'd made all this for me. (Claire).

#### 4. Discussion

The aim of this study was to explore whether the construct of relationship continuity, taken from the field of spousal relationships in dementia, might be useful in describing and understanding the experience of spousal caregivers in ABI. The findings suggested that the two criteria employed for evaluating its applicability were reasonably well met: the self-generated narratives of the participants about their relationship contained plenty of material that related to the five dimensions of relationship continuity, and each participant's account contained material relating to each of these dimensions. Moreover, participants who showed continuity (or discontinuity) on one dimension tended to show continuity (or discontinuity) on the other dimensions. These findings suggest that relationship continuity merits further investigation as a means of understanding the experience of spousal caregivers. Care should be taken not to draw too general a conclusion from this. The study does not provide compelling evidence that the concept of relationship continuity captures something important about the experience of spousal caregivers *generally*, or that caregivers will *generally* show consistency across the dimensions. Quantitative studies using larger representative samples would be required for this. However, the findings do suggest that the concept may provide a useful means of understanding the experience of some spousal caregivers and that it merits further investigation as a means of understanding the experience of spousal caregivers generally.

The correspondence across dimensions was not perfect (see Table 3). For example, despite reporting a discontinuous experience in terms of *same/different person*, *relationship redefined* and *couplehood*, Maureen did not describe her experience in terms of *loss*; and, despite reporting a continuous experience on the other dimensions, Janet's account suggested her experience in terms of *same/different feelings* and *couplehood* represented a mix of continuity and discontinuity. This imperfect correspondence is not unexpected. Relationship continuity/discontinuity is conceptualised as a continuum, not as a dichotomy (Riley et al., 2013). Those who fall towards the middle of the continuum are less likely to show high consistency. Moreover, human relationships are highly complex, and inconsistency and ambiguity of thought and feeling are to be expected. The most that can be expected is that the construct roughly capture some important aspect of them.



The findings of the present study resonate with scattered reports in previous ABI literature. Previous studies have also reported that some (but not all) spouses feel that their partner has become a stranger (Bodley-Scott & Riley, 2015; Gill et al., 2011; Gosling & Oddy, 1999; Hammond et al., 2011; Kratz et al., 2017; Mauss-Clum & Ryan, 1981; Wood, 2005); that some feel more like a parent or a carer than a spouse (Bodley-Scott & Riley, 2015; Gill et al., 2011; Gosling & Oddy, 1999; Hammond et al., 2011; Kratz et al., 2017); that some feel separate from their spouse whilst others feel allied together as partners against the challenges posed by the brain injury (Anderson-Parenté et al., 1990; Bodley-Scott & Riley, 2015; Hammond et al., 2011; Kratz et al., 2017); that some feel continuing love for their spouse, but others report emotional distance and, in some cases, that love has been replaced by more negative emotions (Bodley-Scott & Riley, 2015; Gill et al., 2011; Godwin et al., 2014; Hammond et al., 2011); and that some use the language of loss and grief to describe their feelings about their previous relationship and the pre-injury spouse (Bodley-Scott & Riley, 2015; Godwin et al., 2014; Hammond et al., 2011; Kratz et al., 2017; Ruston, 2007). These previous findings were not, for the most part, explicitly related by their authors to the framework of relationship continuity. Integrating them into this framework has the advantage of highlighting how they may be closely connected (Riley et al., 2013). These connections, in turn, have the potential to provide a richer understanding of how spousal carers experience their relationship with the person with an ABI. For example, a perception of the other person as a stranger may be likely to be accompanied by a perception that the relationship is also very different, by a loss of love and affection and by a greater emphasis on individuality rather than being a couple.

#### **4.1. Potential precursors and consequences of relationship continuity**

Making the connection with the framework of relationship continuity also opens up avenues of investigation about why there are individual differences in the experience of continuity/discontinuity and about the potential implications of relationship continuity for understanding how spouses respond to their role in providing care and support. Exploring these implications may, in turn, improve our understanding of why there are such high rates of relationship dissatisfaction and breakdown following ABI, and the impact that the relationship may have on general psychological well-being and rehabilitation outcomes.

The findings from the present study suggest a number of specific possibilities for further investigation. Again, it is not suggested that the study presents compelling evidence of the link between relationship continuity and these potential precursors and consequences; larger samples and a different methodology would be required to establish this. Rather, the study suggests that these links may occur for some spousal caregivers, and provides evidence that the links merit further research.

In terms of potential precursors, those who more consistently experienced discontinuity (Frank and Joan) also reported a marked lack of emotional reciprocity from their partners; whereas those who more consistently experienced continuity (Claire and Janet) reported the continued expression of love and affection from their partners. It is possible that lack of emotional reciprocity undermines relationship continuity by making it difficult to continue to feel love in return; by eroding the sense of couplehood through the removal of shared moments of enjoyment; and by making it feel no longer like a spousal relationship. The damaging effects of a lack of emotional reciprocity on relationships after ABI have been highlighted in other studies (e.g. Bodley-Scott & Riley, 2015; Gill et al., 2011; Godwin et al., 2014; Gosling & Oddy, 1999).

In terms of the potential impact of perceptions of continuity/discontinuity on how spouses provide care and support, one possibility raised by the present study relates to how the participants understood and managed the changes in their spouse. Janet and Claire (who more consistently perceived continuity) used knowledge of their partner as a person to try to make sense of the changes, and this person-centred understanding enabled them to be more proactive and creative in dealing with the changes. By contrast, those who more consistently perceived discontinuity (Joan and Frank) understood the changes primarily in terms of damage to the brain. Perhaps associated with this (since they did not view themselves as experts in brain damage), they were more reliant on external

support to address problems arising from these changes. Discontinuity involves the perception that the person with the brain injury has become radically different and a stranger. It may be that, in consequence, the pre-injury schema for understanding the behaviour of the spouse no longer seem relevant and are accordingly abandoned in favour of understanding and coping based on the fact that the brain has been damaged. In a qualitative study of spouses in ABI, Bodley-Scott and Riley (2015) likewise suggested that continuity may be associated with using knowledge of the individual to gain a better understanding of challenging behaviour and thereby coping more effectively with it, whereas discontinuity appeared to be associated with a sense of bewilderment about why the behaviour was occurring, and a sense of defeat and hopelessness about the prospect of ever managing the behaviour effectively. Similar differences in the understanding and management of care needs have also been reported in the dementia literature. Walters et al. (2010) suggested that the care approach of those perceiving continuity was characterised by greater efforts to understand the situation from the perspective of the person with dementia, and Chesla et al. (1994) suggested that the care they provided was generally more tailored to the needs of the individual. It was noted in the Introduction that relationships may have an impact on the rehabilitation outcomes for the person with the ABI because of the important part the spouse plays in helping the person achieve those outcomes (Clark & Smith, 1999; Palmer & Glass, 2003; Sander et al., 2002). The role that continuity/discontinuity has in this link between relationship quality and rehabilitation outcomes merits further investigation. Perceptions of continuity may enable a more person-centred approach to assisting the person with a brain injury to achieve their desired rehabilitation outcomes.

It was also noted in the Introduction that the quality of spousal relationships is associated with the general psychological well-being of both parties (Anderson et al., 2002; Epstein-Lubow et al., 2009; Kendall & Terry, 2009). The present findings raise the possibility that part of this association in respect of the care-giving spouse may arise from differences in relationship continuity. The two participants who more consistently perceived discontinuity (Frank and Joan) experienced greater distress and sense of burden, whereas the others felt more able to cope with their situation. Other qualitative studies in acquired brain injury have also reported a link between perceptions of discontinuity and greater subjective burden in both spousal and mother-child relationships (Bodley-Scott & Riley, 2015; Riley & Balloo, 2016). Similarly, in the qualitative literature on relationship continuity in dementia, discontinuity has been associated with greater distress and negative emotional reactions to the care-giving role (Murray & Livingston, 1998; Walters et al., 2010). Tarlow et al. (2004) suggested that caregivers in dementia appraise their caring experience by weighing up the positive experiences of caring against the negative demands placed upon them; and that the positive aspects of caring can act as buffers to reduce the stress experienced from the negative demands. In the present study, the participants who more consistently experienced continuity (Janet and Claire) reported a range of positive experiences arising from the relationship, including the pleasure from the company of their partner, the persistence of loving feelings, the sense of working together to meet the challenges and the thoughtfulness and affection that their partners continued to show. It may be that these positive experiences acted as buffers to reduce the stress experienced from the negative aspects of their situation.

Finally, the role of relationship continuity/discontinuity in whether the relationship breaks down or persists in response to the ABI also merits further investigation. Joan and Frank, who were more discontinuous in their perceptions, both reported that they had often considered leaving; whereas Claire, who was consistently continuous, dismissed this as a possibility. Bodley-Scott and Riley (2015) also reported a potential link between discontinuity and thoughts of leaving the relationship. Discontinuity involves a loss of love and affection for the spouse. Unsurprisingly, a loss of love and affection has been highlighted in general research on romantic relationships to be a major factor in the breakdown of such relationships (Huston, 2009; Kayser, 1993).

#### 4.2. Limitations

As already noted and as is the nature of qualitative research, the findings should not be over-generalised. The findings suggest the usefulness of the framework for understanding the experience of some spousal caregivers, but no claims are made about how generally applicable it might be. Drawing such conclusions would require quantitative studies using larger and more representative samples.

It is worth highlighting several ways in which the experiences of the participants in this study cannot be considered to be representative of the full range of experience of spouses after ABI. First, given that their partner with the ABI was receiving brain injury rehabilitation at least one year after the injury, and given the challenges of providing care highlighted by the participants in their interviews, it was apparent that the spouses of all the participants had experienced a relatively severe ABI. It may be that relationship continuity provides a less useful framework for understanding the experiences of those whose spouse has had a less severe injury that may pose fewer challenges to the relationship. Moreover, only one of the participants' partners had had a stroke. It was evident from the interview data that the stroke had affected his personality and behaviour in a way that is common in severe traumatic brain injury, but is less frequent in stroke. Relationship continuity may not be useful for understanding the experience of those whose partner's stroke has primarily affected their physical ability. The small size of the sample also indicates the need for caution in generalising even to those who match the demographic and injury-related profile of those who took part. However, the commonalities their experiences share with existing ABI and dementia literature do suggest the wider relevance of the findings to clinical practice and research.

There was some heterogeneity in the sample in that Joan's partner was the only one who had a stroke (rather than a traumatic brain injury) and the time post-injury was also longer than the other participants (Table 1). However, as already noted, the stroke had affected his personality and behaviour in a way that is common in severe traumatic brain injury. Also, despite the time post-injury, Joan was clearly able to recall how her partner and their relationship had been before the stroke and how they had changed after it.

The methodology of the study was somewhat unusual in that it used, in part, a predetermined thematic framework to analyse the data. This raised the risk of imposing a structure on the experiences of the participants that did not faithfully capture their experience. To combat this, considerable care was taken during the interviews to avoid using questions that may have biased the participants towards using the language and concepts of relationship continuity. Excerpts from the interviews have also been used frequently in this report as evidence that the language and concepts were used by the participants, rather than imposed during the interpretation stage.

#### 5. Conclusions and implications

The study suggests that the construct of relationship continuity may have value in understanding the experience of some spouses after an ABI. It may help to draw together different aspects of their experience, suggesting connections between them and implications arising from them. This richer understanding may assist clinicians who support spouses in dealing with the impact of a brain injury.

In terms of future research, the findings suggest the potential value of a more detailed investigation of why some spouses perceive continuity in their relationship but others do not; and into the impact of relationship continuity on the long-term stability of the relationship, the general psychological well-being of those involved, progress in rehabilitation, and how spouses respond to the challenges of the ABI. If continuity has a positive impact on these outcomes, research would be merited on whether it is possible to encourage spouses to maintain their perceptions of continuity in the relationship.

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